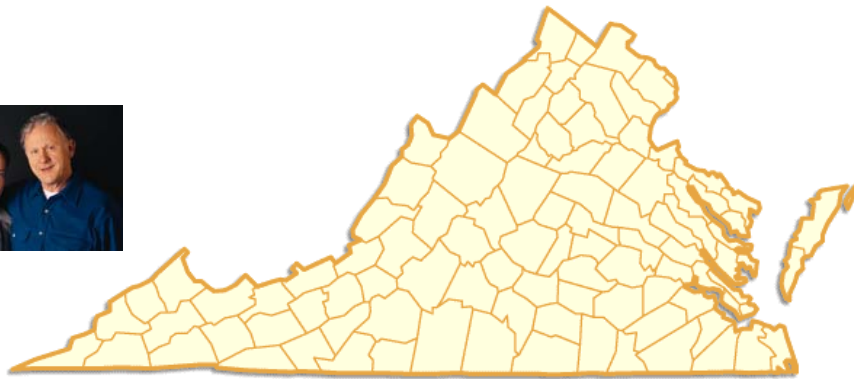


MR Family Survey 2003



February 2004

Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services
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EXECUTIVE SUMMARY

Background

The Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services has identified family satisfaction and perceptions of Community Service Boards' (CSBs) and Behavioral Health Authorities' (BHAs) services as a performance measure to be assessed on an annual basis. The Department administered its fourth annual statewide survey of family satisfaction with CSB mental retardation services in 2003.

The family satisfaction survey was designed to measure family perceptions of community-based services in the following domains:

- Family Involvement
- Case Management Services
- Choice and Access
- Health and Safe Environment
- Service Reliability

Response Rate and Sample Size

- Thirty-six CSBs completed and returned a total of 920 surveys – a 32% reduction from the previous year.
- Due to the manner in which the surveys were distributed, a precise response rate is unattainable. The estimated response rate statewide was 10.6%.
- The number of surveys received per CSB ranged from 1 to 106.
- About 15% of the surveys were returned with unusable provider ID numbers.
- Almost 20% of the forms could not be scanned and had to be hand-entered, increasing the possibility of data entry-related error.

Demographics

- Of the sample, 54.9% were male, 73.1% were identified as White Non-Hispanic, and 23.2% were African-American Non-Hispanic, very similar to the demographics from the previous year.
- Approximately 61.3% of the individuals completing the survey were between 23 and 59 years of age.
- Nearly 76.9% of the individuals with mental retardation lived at home with their parents, 8.5% with a brother or sister, and 14.6% indicated "Other" as the primary living arrangement.

Domains

- Overall, about 45% responded positively on the family involvement domain up from 38.4% for the previous year.
- About 65% of the respondents had a positive perception with regard to the choice and access domain, similar to the previous year.

- About 85% scored positively on the case management services domain, similar to the previous year.
- About 88% scored positively on the healthy and safe environment domain, similar to the previous year.
- About 51% responded positively on the service reliability domain, a substantial increase from the 5% for the previous year.

Conclusions

- The majority of family members/guardians of individuals with mental retardation continue to report positive perceptions of the services received through CSBs on several domains.
- With regard to negative perceptions, on the Family Involvement domain, about 23% report being able to choose the agencies or providers that serve the person with mental retardation. About 58% report having no choice about the support staff that worked directly with the person.
- With regard to the service reliability domain, over 25% indicated that frequent changes in case managers had been at least “somewhat” of a problem, and about 41% indicated that frequent changes in direct staff had been a problem as well. Both questions show improvement over the previous year.
- About 96% agreed that services provided to the person with mental retardation have helped the person to reach planned goals over the past year. About 92% agreed that the services provided helped the person with mental retardation to gain at least one new skill or ability over the past year.
- For overall quality of life, about 52% felt that the person with mental retardation was better off this year. Over 88% felt that the CSB services had a positive impact on the person. A little over 41% felt that the person with mental retardation had progressed better or the same as expected.

Limitations

- Considerable variability was found in the number of surveys received from CSBs. The number of surveys received ranged from 1 to 109 making it difficult to analyze data at CSB level.
- The results of this survey reflect the perceptions of only those family members/guardians who had a family member with mental retardation receiving case management and chose to complete the survey, thus the survey is open to self-selection biases.
- Finally, because the survey is a cross-sectional design, these findings represent the perceptions of family members/guardians only at the time of the survey. Perceptions and attitudes are subject to change over time.

Despite these limitations, the survey clearly contributes a greater understanding of family member/guardian perception about publicly funded mental retardation services. The surveys will be important contributions to continuous improvement for the CSBs for both Waiver and Non-Waiver services.

BACKGROUND

The Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) has identified family satisfaction and perceptions of Community Service Boards' (CSBs) and Behavioral Health Authorities' services as a performance measures to be assessed on an annual basis. DMHMRSAS administered its fourth annual statewide survey of family satisfaction with CSB mental retardation services in 2003.

DMHMRSAS completed the first family/guardian survey for individuals with mental retardation in 2000. The Mental Retardation Services Survey 2000 was based on surveys developed through the National Core Indicators Project (NCI)¹. DMHMRSAS participated in the NCI from 1997 through 1999. This participation has provided Virginia with direct access to the work of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI), including data collection instruments. The survey also provided DMHMRSAS an opportunity to identify improvements that could be made to the survey before the next version was implemented statewide in January 2002. The survey was conducted again in 2003, and is currently being conducted for 2004, which will allow for more useful trend analyses.

METHOD

Measure

The instrument used for this project was the 27-item close-ended questionnaire based on surveys developed by the National Core Indicators Project (NCI). The National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) sponsored this project.

The family satisfaction survey was designed to measure family perceptions of community-based services in the following domains:

- Family Involvement
- Case Management Services
- Choice and Access
- Health and Safe Environment
- Service Reliability

Response options for the questions used to create the domains ranged from "1" to "3" with "1" representing "Yes/Mostly Agree", "2" representing "Somewhat", and "3" representing "No, not at all". For each domain, a minimum number of questions had to be completed in order to create a valid measure for that domain. The mean score of the domain was then computed and used as

¹ The National Core Indicator Project combines the research activities of twenty-three states with a focus on improving the evaluation of services to persons with mental retardation.

the overall domain score, thus scores of “1.5” or less on a domain indicate a positive feeling on that particular domain.

Sample

The questionnaire was administered to family members/guardians of individuals 18 years of age or older with mental retardation receiving a minimum of active case management and who may be receiving other CSB services. Children’s families were not surveyed since the instrument was not validated for use with children. To be included in the survey, consumers had to have received services from a CSB for 12 months or more prior to the survey period. Surveys were distributed to a family member or guardian attending an annual planning meeting, to be completed afterward and mailed. If a family member/guardian was not present during the annual meeting, the case manager mailed the survey with an instruction sheet to the family member. Surveys and instructions sheets were provided in Spanish when needed. All surveys were completed after an annual planning meeting and not in the presence of case managers or other staff. Case managers were encouraged to emphasize the importance of the survey to family members/guardians. Completed surveys were mailed directly to the Office of Mental Retardation in a pre-paid return address envelope.

Due to the manner in which the survey was distributed, the exact number of surveys distributed was not available. Approximately 8,649 surveys were distributed of which 920 surveys were returned for a response rate of approximately 10.6%. Of the 920 returned surveys about 15% (60) were returned with either blank or unusable provider ID numbers. These were included in the sample for analysis pertaining to the state.

Analyses

Forty CSBs participated in the family survey during the past calendar year. Surveys that could be attributed to specific CSBs were returned from thirty-six boards. For statewide representative sample at the 95% confidence level with a 5% confidence interval, at least 368 surveys were needed. A total of 920 total surveys were received, ranging from 1 to 109 per CSB. Table 1 (next page) presents the number of surveys per CSB in the final sample, the percent of the sample, the approximate number of surveys distributed and the approximate rate of return by CSB. An example of the *Mental Retardation Services Family Survey* can be found in the Appendix.

Table 1: Survey Response Analysis

Provider	Surveys Returned	% of Sample	# Active CM	% Rate of Return
Alexandria CSB	-	-	101	-
Alleghany-Highlands CSB	3	0.31%	46	6.5%
Arlington CSB	20	2.04%	112	17.9%
Central Virginia CSB	-	-	489	-
Chesapeake CSB	40	4.09%	185	21.6%
Chesterfield CSB	31	3.17%	309	10.0%
Colonial MH & MR Services	10	1.02%	120	8.3%
Crossroads CSB	21	2.15%	155	13.5%
Cumberland Mountain	9	0.92%	96	9.4%
Danville-Pittsylvania	21	2.15%	144	14.6%
Dickenson CSB	3	0.31%	19	15.8%
Eastern Shore CSB	16	1.64%	107	15.0%
Fairfax-Falls Church CSB	80	8.18%	715	11.2%
Goochland-Powhatan	1	0.10%	35	2.9%
Hampton-Newport News	2	0.20%	1007	0.2%
Hanover County CSB	36	3.68%	78	46.2%
Harrisonburg-Rockingham CSB	23	2.35%	191	12.0%
Henrico Area MH & MR Services	57	5.83%	293	19.5%
Highlands Community Services	-	-	135	-
Loudoun County CSB	6	0.61%	70	8.6%
Middle Peninsula-Northern Neck CSB	35	3.58%	198	17.7%
Mount Rogers CSB	21	2.15%	182	11.5%
New River Valley Community Services	19	1.94%	109	17.4%
Norfolk CSB	19	1.94%	300	6.3%
Northwestern Community Services	1	0.10%	231	0.4%
Piedmont Community Services	-	-	174	-
Planning District I CSB	25	2.56%	192	13.0%
PD 19	11	1.12%	144	7.6%
Portsmouth	23	2.35%	236	9.7%
Prince William County CSB	36	3.68%	150	24.0%
Rappahannock-Area	45	4.60%	326	13.8%
Rappahannock-Rapidan CSB	28	2.86%	145	19.3%
Region Ten CSB	11	1.12%	211	5.2%
RBHA	45	4.60%	272	16.5%
Blue Ridge Behavioral Health	68	6.95%	377	18.0%
Rockbridge Area CSB	11	1.12%	86	12.8%
Southside CSB	16	1.64%	195	8.2%
Valley CSB	14	1.43%	168	8.3%
Virginia Beach	109	11.15%	435	25.1%
Western Tidewater CSB	4	0.41%	111	3.6%
Statewide	920	94.07%	8,649	10.6%

RESULTS

Consumer/Family Characteristics

The background information on consumer and family demographics, as reported by the family/guardian, is presented in Table 2. Given the sample size, we can expect that the sample represents the statewide demographics of consumers with mental retardation, served by CSBs, who are over 18 years old and receive at least case management services and may receive additional services such as residential, respite or day/employment support.

Of the sample, 54.9% of the consumers were male, 73.1% were identified as White Non-Hispanic, and 23.2% were African-American Non-Hispanic. Approximately 61.3% of the individuals completing the survey were between 23 and 59 years of age. A parent completed 64.4% of the surveys, 16% were completed by a brother or sister, and 19.3% indicated “Other” as the relationship. Of the persons completing the survey, a little more than half (53.4%) indicated that the person with mental retardation lived with them. Twenty-five percent indicated that they saw the person with mental retardation about once a week, and 13.6 % indicated they saw the person about once a month. Selection of the surveys completed as the person with mental retardation “lives with me” combined with the relationship to the consumer question indicates that about 77% of the consumers live with their parents, about 15% live in an arrangement denoted as “Other” and about 8% live with a sibling.

Table 2: Consumer and Family Demographics

Demographic Survey Question (N=Respondents)		Percentage
What is the race of the person with mental retardation?		
N = 872	Alaskan Native	0%
	Asian Pacific Islander	1.6%
	White-Non Hispanic	73.1%
	American Indian	0.2%
	African American	23.2%
	Hispanic	0.85%
	Other	1.1%
What is the gender of the person with mental retardation?		
N = 905	Male	54.9%
	Female	45.1%
What is the age of the person completing the survey?		
N = 952	Under 18	0.9%
	18-22	2.2%
	23-59	61.3%
	60-64	13.4%
	65-74	14%
	75+	8.1%

What is the relationship of the person completing the survey to the person with mental retardation?		
N = 952	Parent	64.4%
	Sibling	16%
	Spouse	0.3%
	Other	19.3%
How often does the person completing the survey see the person with mental retardation?		
N = 942	Lives with me	53.4%
	Once a week	25.1%
	Once a month	13.6%
	A few times a year	6.1%
Where does the person with mental retardation live?		
N=472	Parent	76.9%
	Other	14.6%
	Sibling	8.5%

These demographics are similar to those of the 2002 survey. For more detail and a complete comparison with 2002 data, refer to Table 6. *Demographic Data* in the Appendix.

Outcome Domains Subscales

Factor analysis helps reduce a list of items into groups of items that measure a concept. Factor analysis of the Family Survey items from 2002 revealed five subscales or groups of individual questions that address the same topic. The data from the 2003 survey were subjected to factor analysis as well to verify the validity of the subscales. Both years of data were analyzed using the same five domains for this report, in order to make year-to-year comparisons. The five domains are:

- Family Involvement.
- Case Management Services
- Choice and Access
- Healthy and Safe Environment
- Service Reliability

The mean and the standard deviation scores, as well as the number of responses are presented for each survey question in Table 3. Lower mean scores indicate greater satisfaction. Table 3 also shows the survey questions that are contained in each subscale and percentage of responses that are positive (% Agree) and negative (% Disagree) for 2002 and 2003. For the Agree % column, note that this category includes the responses “Yes/Mostly” and “Somewhat”. The Disagree % column includes the response “No, not at all”.

Table 3: Domain Responses

	Mean ¹	Std. Dev.	N	% Agree ²	% Disagree ²
Family Involvement					
Over the past year, have the services provided to the person with mental retardation helped to relieve stress on your family?					
2003	1.36	0.6	846	93.5	6.5
2002	1.36	0.61	1,160	92.8	7.2
Did you help develop the person's yearly plan?					
2003	1.45	0.7	915	87.8	12.2
2002	1.5	0.72	1,219	86.5	13.5
Do you help choose the agencies or providers that serve the person with mental retardation?					
2003	1.66	0.83	866	76.6	23.4
2002	1.71	0.84	1,169	75.1	24.9
Do you help choose the support staff that work directly with the person with mental retardation?					
2003	2.35	0.84	820	41.6	58.4
2002	2.41	0.83	1,144	37.1	62.9
Do staff talk to you about different ways to meet your family's needs?					
2003	1.52	0.7	862	87.9	12.1
2002	1.6	0.74	1,150	84.7	15.3
Do staff respect your family's choices and opinions?					
2003	1.18	0.41	885	98.6	1.4
2002	1.23	0.49	1,188	97.1	2.9
Case Management					
Overall, has the case manager been helpful?					
2003	1.14	0.39	941	98.3	1.7
2002	1.16	0.4	1,274	98.5	1.5
Did you get enough information to help you participate in planning services for the person with mental retardation?					
2003	1.29	0.55	917	95.2	4.8
2002	1.3	0.57	1,243	94.3	5.7
Can you contact the case manager whenever you want to?					
2003	1.1	0.34	944	98.7	1.3
2002	1.1	0.34	1,262	98.8	1.2
When you ask the case manager for assistance, does he/she help you to get what you need?					
2003	1.13	0.39	926	98.4	1.6
2002	1.14	0.39	1,229	98.5	1.5
Choice and Access					
If the person with mental retardation does not speak English or uses a different way to communicate, are there enough staff available to communicate with him/her?					
2003	1.3	0.57	443	94.6	5.4
2002	1.37	0.61	640	93.1	6.9
Do you feel that the person with mental retardation has access to the special equipment or accommodations that he/she needs?					
2003	1.26	0.55	596	94.6	5.4
2002	1.27	0.55	842	94.5	5.5
Do you feel that supports and services are available for the person with mental retardation when needed?					
2003	1.27	0.49	948	97.9	2.1
2002	1.31	0.53	1,275	96.6	3.4

	Mean ₁	Std. Dev.	N	% Agree ²	% Disagree ²
Overall, are you satisfied with the services and supports the person with mental retardation currently receives?					
2003	1.23	0.48	954	97.3	2.7
2002	1.26	0.52	1,293	96.2	3.8
If you or the person with mental retardation ever asked for the agency's assistance in an emergency or crisis, was help provided right away?					
2003	1.3	0.6	625	92.5	7.5
2002	1.32	0.62	857	91.6	8.4
Do staff help the person with mental retardation get supports in the community?					
2003	1.44	0.69	805	88.7	11.3
2002	1.48	0.7	1,092	87.9	12.1
Are there enough agencies that provide services to people with mental retardation in your area so that you may choose one in addition to your local CSB?					
2003	2	0.86	627	63.2	36.8
2002	2.03	0.89	848	58.8	41.2
Are you satisfied with the way complaints about services are handled?					
2003	1.34	0.58	784	94.6	5.4
2002	1.39	0.62	1,070	92.6	7.4
Healthy and Safe Environment					
Do you feel that where the person with mental retardation goes during the day is a healthy and safe environment?					
2003	1.09	0.3	895	99.4	0.6
2002	1.09	0.32	1,203	99	1
Do you feel that where the person with mental retardation lives is a healthy and safe environment?					
2003	1.06	0.26	955	99.7	0.3
2002	1.09	0.32	1,287	98.8	1.2
Service Reliability					
Frequent changes in staff who work directly with the consumer have not been a problem. (Question on survey was a negative indicator; values were reversed for clarity.)					
2003	1.56	0.73	829	58.6	41.4
2002	2.34	0.74	1,151	16.3	83.7
Frequent changes in case managers have not been a problem. (Question on survey was a negative indicator; values were reversed for clarity.)					
2003	1.34	0.63	761	74.9	25.1
2002	2.63	0.64	1,069	9.1	90.9
Other MR					
Do you feel that services provided to the person with mental retardation have helped him/her to reach planned goals over the past year?					
2003	1.34	0.54	919	96.4	3.6
2002	1.37	0.58	1,235	95	5
Do you feel that services provided to the person with mental retardation have helped him/her to gain at least one new skill or ability over the past year?					
2003	1.43	0.64	893	92	8
2002	1.45	0.67	1,181	89.9	10.1

¹Scale ranges from 1: 'Yes/Mostly' to 3: 'No, Not At All'. Lower mean scores correspond with greater satisfaction.

²For standard questions, percentages in the Agree column include those who responded 'Yes/Mostly' and 'Somewhat'; percentages in the Disagree column include those who responded 'No, Not At All'. For reverse-coded questions, percentages in the 'Agree%' column include those who answered 'No, Not At All'; the 'Disagree%' column includes those who answered 'Yes/Mostly' and 'Somewhat'.

Family Involvement

For the year 2003, about 45% responded positively on the family involvement domain, an improvement over the 38% responding positively for the previous year. About 85% agreed that staff talked to them about different ways to meet the family needs. About 99% agreed that staff respected the family's choices and opinions, and about 94% responded that services had helped to relieve stress on the family. On the negative side, only 42% agreed that they had any choice in selection of the support staff for the person with mental retardation, and only 77% agreed that they had any choice in the agencies or service providers.

Case Management Services

About 85% scored positively on the case management services domain, similar to the previous year. Nearly 98% of family members reported being able to contact the case manager whenever they wanted to, and that overall the case manager was helpful.

Choice and Access

About 65% of the respondents had a positive perception with regard to the choice and access domain, similar to the previous year. About 98% agreed that supports and services were available in the community for the person with mental retardation and that they were overall satisfied with the services and supports currently received by the person. About 89% agreed that staff helped the person with mental retardation obtain supports and services in the community. Over 95% responded positively that the person with mental retardation had access to special equipment or accommodations. Only 64% agreed that there were enough agencies in their area that they were able to choose one in addition to their local CSB.

Healthy and Safe Environment

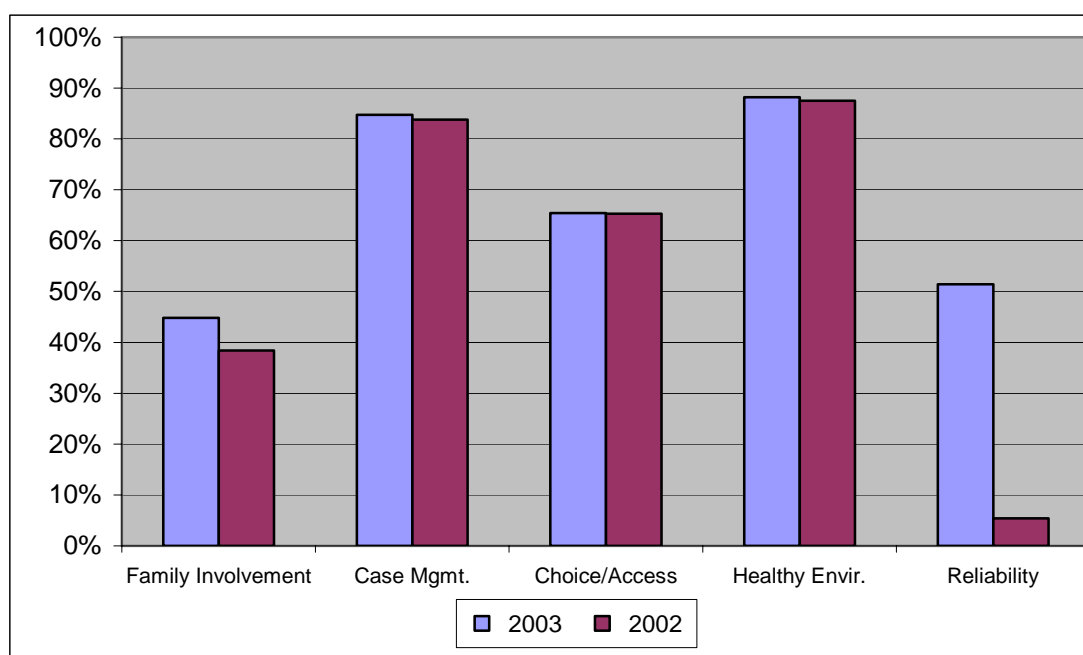
About 88% scored positively on this domain, very similar to the responses from the previous year. Almost all of family members surveyed considered the environment where the consumer went during the day as a healthy and safe one, and the same was true for the place of residence as safe and healthy for the consumer.

Service Reliability

About 50% responded positively on this domain a dramatic improvement from the previous year. Whereas in 2002, over 90% indicated that frequent changes in case managers had been at least "somewhat" of a problem in 2003, only about 25% indicated this as a current problem. For 2002 over 84% indicated that frequent changes in direct staff had been at least "somewhat" of a problem, while in 2003, only 41% indicated this to be true.

Figure 1 (next page) presents the percentage of positive responses for each of the five domains for both years of data.

Figure 1: Percentage of Positive Responses Per Domain



Overall Perception of Services

Table 4 provides the results for the quality of life questions. About 52% felt that the person with mental retardation was better off this year. About 88% felt that the CSB services had a positive impact on the person. A little over 41% felt that the person with mental retardation's progress had been better than expected.

Table 4: Overall Perception of Services Results

	Mean ¹	Std. Dev.	N	% Satisfied ²	% Dissatisfied ²
Overall, do you feel that the person with mental retardation is better off than, the same as, or worse off than last year?					
2003	1.51	0.57	909	52.4	3.9
2002	1.52	0.57	1,278	52.1	3.8
Do you feel that CSB services have had a positive impact, no impact, or a negative impact on the person with mental retardation this past year?					
2003	1.13	0.38	882	88.2	1.6
2002	1.15	0.41	1,235	87.4	2.2
Overall, do you feel that the person with mental retardation's progress has been better than expected, the same as expected, or not as good as expected?					
2003	1.67	0.62	901	41	8
2002	1.68	0.62	1,281	40.7	8.3

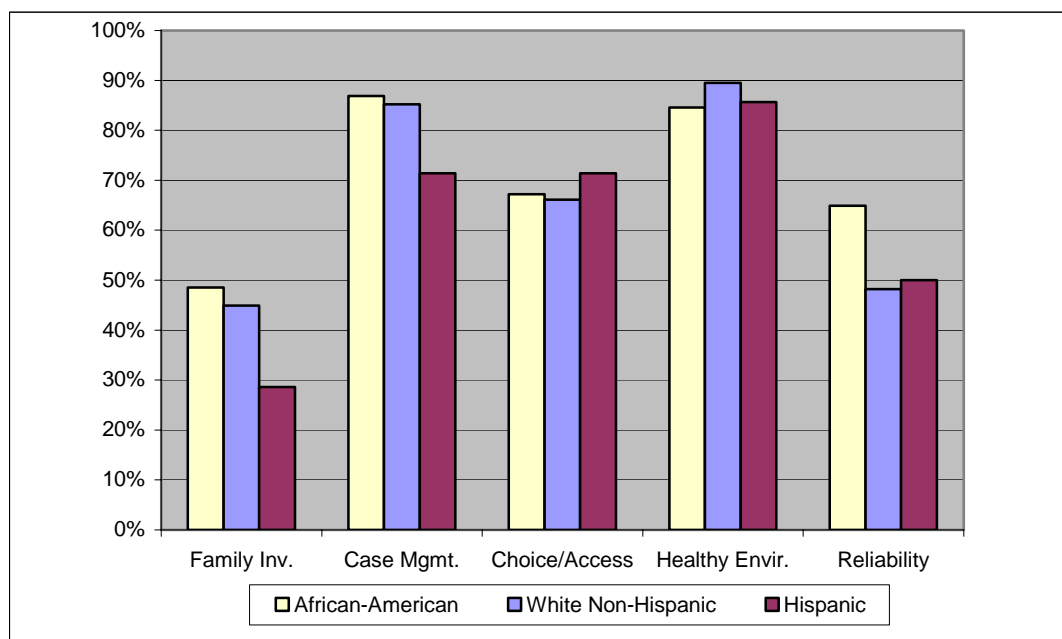
¹Scale ranges from 1: 'Better Off' to 3: 'Worse Off'. Lower mean scores correspond with greater satisfaction.

²Percentages in the Satisfied column include those who responded 'Better Off'. Percentages in the Dissatisfied column include those who responded 'Worse Off'. Percentages for consumers who responded 'The Same' are not shown, but can be calculated by subtracting the sum of the '% Satisfied' and '% Dissatisfied' columns from 100%.

Outcome Domains by Demographics

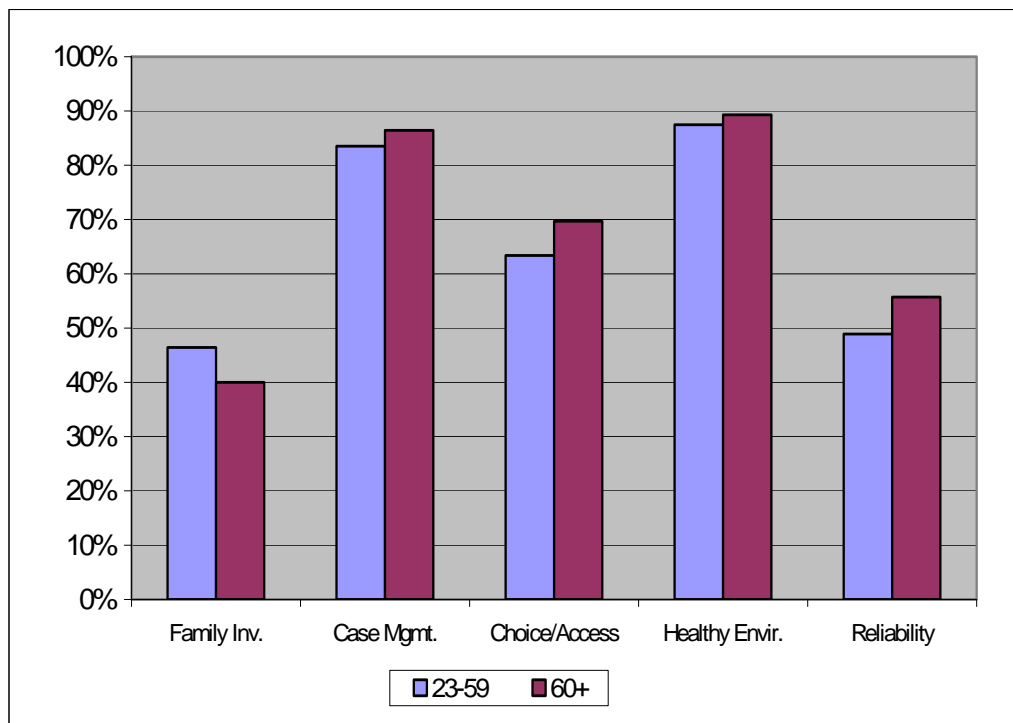
The percentage of respondents expressing satisfaction on the five domains has been distributed by the demographic variables. All of these values are presented in **Table 7. Percentage of Survey Respondents Expressing Satisfaction** in the Appendix. One of the most notable differences occurs when the percentages of respondents expressing satisfaction are examined by race categories. Families of African-American consumers expressed higher percentages of positive responses than families of White consumers on four domains: Family Involvement (48.5% vs. 44.9%), Case Management (86.9% vs. 85.2%), Choice/Access (67.2% vs. 66.1%) and Reliability (64.9% vs. 48.2%). For the domain of Healthy Environment, families of White consumers expressed greater satisfaction than did families of African-American consumers (89.5% vs. 84.6%). See Figure 2.

Figure 2: Outcome Domains by Demographics



Another difference in the percentages of respondents expressing satisfaction among the five domains is by the age of the person completing the survey. Older individuals completing the survey – those aged 60 or above, express higher levels of satisfaction on four of the five domains. Those over the age of sixty express greater satisfaction on the domains of Case Management (86.4% vs. 83.5%), Choice/Access (69.7% vs. 63.4%), Healthy Environment (89.3% vs. 87.5%) and Reliability (55.7% vs. 48.9%) than the individuals who are between the ages of 23 and 59. The younger individuals completing the survey are more likely to express satisfaction on the domain of Family Involvement (46.4% vs. 40%). See Figure 3 (next page).

Figure 3: Outcome Domains by Age Range



Outcome Domains by CSB Clusters

Cluster analysis is a statistical procedure that identifies relatively homogenous groups of cases (for this report, CSBs) based on selected characteristics. CSBs in a “cluster” may not be alike on all the selected characteristics, however, when these characteristics are taken together, the “clustered” CSBs will tend to be more similar to each other than to CSBs in other clusters.

Clusters were defined based on previous literature input from CSB representatives and consumer advocates. The following characteristics were used:

- The percentage of unemployed persons in the CSB catchment area;
- The percentage of White, Non-Hispanic residents in the catchment area;
- The population density of the catchment area;
- The percentage of persons living in poverty;
- The budget of the CSB;
- The percentage of combined mental health and substance disorder dollars that were fee generated.

Based on the analysis of the 6 variables, the following clusters were identified:

Cluster 1: Alexandria, Arlington, Fairfax-Falls Church, Hampton/Newport News, Henrico Area, Norfolk, Richmond, Portsmouth, and Virginia Beach.

Cluster 2: Allegheny-Highlands, Cumberland Mountain, Dickenson County, Highlands, Mt. Rogers, New River Valley, Northwestern, Planning District 1, Rockbridge Area, and Valley.

Cluster 3: Crossroads, Danville-Pittsylvania, District 19, Eastern Shore, Middle Peninsula/Northern Neck, Southside, And Western Tidewater.

Cluster 4: Blue Ridge, Central Virginia, Chesapeake, Chesterfield, Colonial, Goochland-Powhatan, Hanover, Harrisonburg-Rockingham, Loudoun, Piedmont Regional, Prince William, Rappahannock Area, Rappahannock-Rapidan, and Region 10.

Figure 4 geographically displays the clusters of CSBs.

Figure 4: CSB Clusters

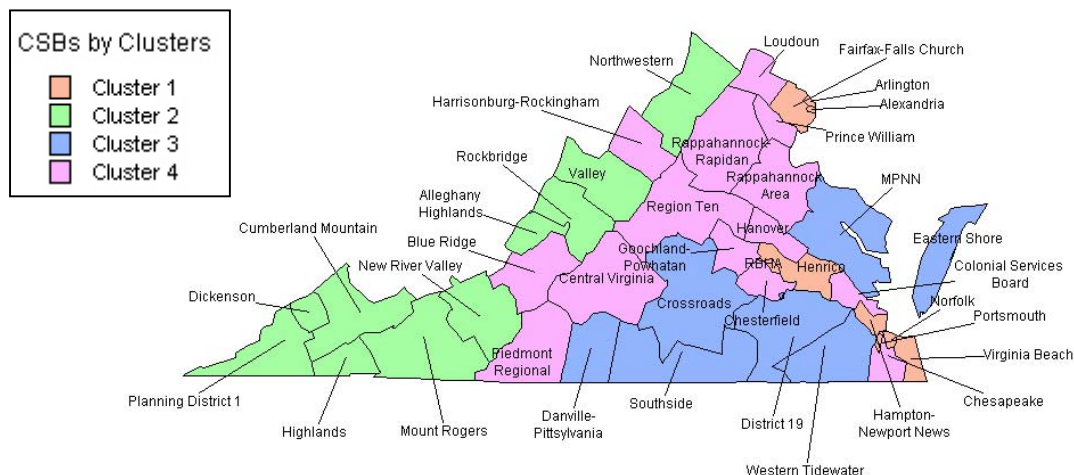
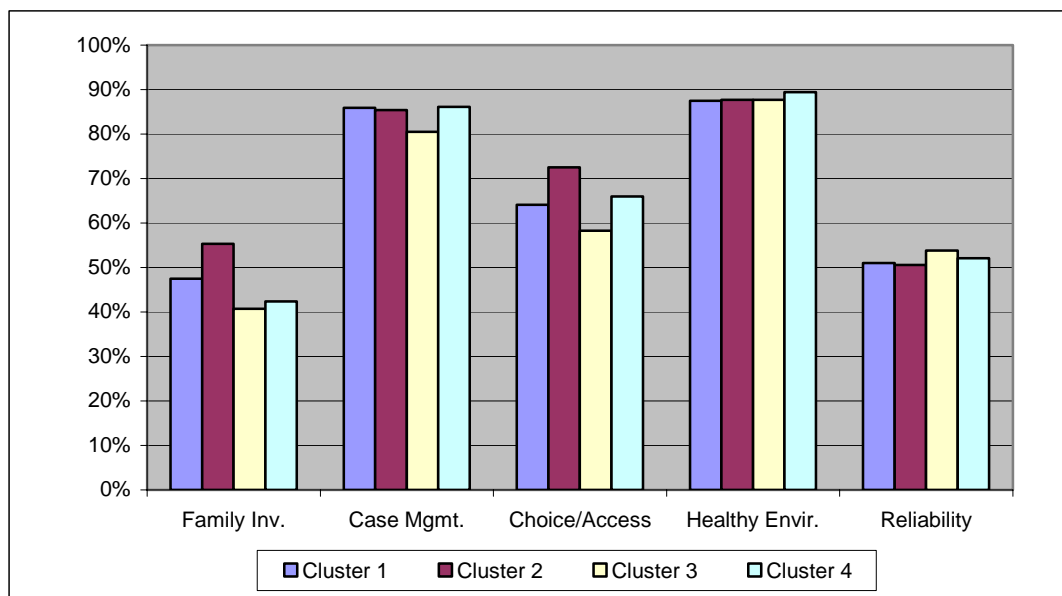


Figure 5 presents the percentages of positive responses on the five domains for the different clusters. Respondents in Cluster 2 were more likely to express satisfaction on the Family Involvement domain (55.3%) than those in the other clusters. These respondents were also more likely to express satisfaction on the Choice/Access domain (72.5%) than were the other clusters. The other three domains remained similar across the different clusters.

Figure 5: Positive Responses Per Domain Per Cluster



COMPARISONS WITH NATIONAL CORE INDICATORS

The National Core Indicators Project (NCI) for the 2002/2003 fiscal year has split their family surveys into two categories: 1) those with developmental disabilities 18 and older who live at home, and 2) those who live outside of the home. Virginia combines both categories into one survey. The two NCI surveys have many of the same or similar items as the Virginia survey, however, the response categories differ slightly, having three choices: 1) always or usually, 2) sometimes, and 3) seldom or never. The Virginia response selections were: 1) yes/mostly, 2) somewhat, and 3) no, not at all. With 400 usable response rates from the sample surveys in each of the six states, NCI reported reasonable comparisons across states within a confidence level of $\pm 10\%$. The data reported for 2002/2003 were 2,854 total (usable) surveys returned for those living outside the family home, and a return of 2,504 surveys for those living in the family home. Thus, with Virginia having a return rate of 920 for 2003 and 1,420 in 2002, some basic comparisons can be made as seen in the chart below. The NCI percentages are the average for all the states reporting that year. Where questions have the same intent, but are worded differently, the NCI question is qualified by the living arrangement (in home or outside of home).

Table 5: Comparison with NCI Survey Data

	N	% Agree ²	% Disagree ²
Family Involvement			
Did you help develop the person's yearly plan?			
2003	915	87.8	12.2
2002	1,219	86.5	13.5
NCI /living outside of the family home	2,315	63.7	13.7
NCI/living at home	1,716	73.5	9.6
Do you help choose the agencies or providers that serve the person with mental retardation?			
2003	866	76.6	23.4
2002	1,169	75.1	24.9
NCI /living outside of the family home			
NCI/living at home	1796	56.6	21.5
Do you help choose the support staff that work directly with the person with mental retardation?			
2003	820	41.6	58.4
2002	1,144	37.1	62.9
NCI /living outside of the family home	2,171	17.5	69.5
NCI/living at home	1,716	36.1	42.5
Do staff talk to you about different ways to meet your family's needs?			
2003	862	87.9	12.1
2002	1,150	84.7	15.3
NCI /living outside of the family home (did you help develop the plan?)	2,315	63.7	13.7
NCI/living at home (did you help develop the plan?)	1716	73.5	9.6
Do staff respect your family's choices and opinions?			
2003	885	98.6	1.4
2002	1,188	97.1	2.9
NCI / outside (staff who assist you with planning respectful and courteous?)	2,559	93.4	.9
NCI/at home (staff respect your choices and opinions?)	2,003	76.9	6.2

Case Management			
Overall, has the case manager been helpful?			
2003	941	98.3	1.7
2002	1,274	98.5	1.5
NCI /outside home (staff who assist with planning are generally effective)	2,476	76.4	2.5
Did you get enough information to help you participate in planning services for the person with mental retardation?			
2003	917	95.2	4.8
2002	1,243	94.3	5.7
NCI /living outside of the family home	2,617	74.3	5.0
NCI/living at home	2,171	52.9	16.9
Can you contact the case manager whenever you want to?			
2003	944	98.7	1.3
2002	1,262	98.8	1.2
NCI /outside home (contact staff who help with planning whenever you want to?)	2,543	88	1.9
NCI/at home (contact staff who help with planning whenever you want to?)	2,065	80.9	4.6
When you ask the case manager for assistance, does he/she help you to get what you need?			
2003	926	98.4	1.6
2002	1,229	98.5	1.5
NCI /living outside of the family home	2,529	81.9	1.9
NCI/living at home	2,070	70.7	6.2
Choice and Access			
If the person with mental retardation does not speak English or uses a different way to communicate, are there enough staff available to communicate with him/her?			
2003	443	94.6	5.4
2002	640	93.1	6.9
NCI /living outside of the family home	1,026	72.8	6.7
NCI/living at home	387	48.3	21.8
Do you feel that the person with mental retardation has access to the special equipment or accommodations that he/she needs?			
2003	596	94.6	5.4
2002	842	94.5	5.5
NCI /living outside of the family home	1,470	85.1	2.7
NCI/living at home	752	62.6	20.1
Do you feel that supports and services are available for the person with mental retardation when needed?			
2003	948	97.9	2.1
2002	1,275	96.6	3.4
NCI /outside home (does family get the services and supports you need?)	2,657	79.8	1.5
NCI/at home (does family get the services and supports you need?)	2,127	61.5	8.2
Overall, are you satisfied with the services and supports the person with mental retardation currently receives?			
2003	954	97.3	2.7
2002	1,293	96.2	3.8
NCI /living outside of the family home	2,729	81.4	1.9
NCI/living at home	2,263	66.9	7.0
Do staff help the person with mental retardation get supports in the community?			
2003	805	88.7	11.3
2002	1,092	87.9	12.1
NCI /living outside of the family home (has access to community activities?)	2,473	60.3	6.3
NCI/living at home (has access to community activities?)	1,960	46.7	16.8
Are you satisfied with the way complaints about services are handled?			
2003	784	94.6	5.4
2002	1,070	92.6	7.4
NCI /living outside of the family home	1,739	64.6	6.8
NCI/living at home (and resolved)	965	59.1	12.8

Healthy and Safe Environment			
Do you feel that where the person with mental retardation goes during the day is a healthy and safe environment?			
2003	895	99.4	0.6
2002	1,203	99	1
NCI /living outside of the family home	2,359	88.8	0.9
NCI/living at home	1,894	82.9	3.3
Do you feel that where the person with mental retardation lives is a healthy and safe environment?			
2003	955	99.7	0.3
2002	1,287	98.8	1.2
NCI /living outside of the family home	2,713	88.1	1.0
Service Reliability			
Frequent changes in staff who work directly with the consumer have not been a problem. (Question on survey was a negative indicator; values were reversed for clarity.)			
2003	829	58.6	41.4
2002	1,151	16.3	83.7
NCI /living outside of the family home	2,294	28.3	22.8
NCI/living at home	1,762	37.1	20.1

¹Scale ranges from 1: 'Yes/Mostly' to 3: 'No, Not At All'. Lower mean scores correspond with greater satisfaction.

²For standard questions, percentages in the Agree column include those who responded 'Yes/Mostly' and 'Somewhat'; percentages in the

Disagree column include those who responded 'No, Not At All'. For reverse-coded questions, percentages in the 'Agree%' column include those who answered 'No, Not At All'; the 'Disagree%' column includes those who answered 'Yes/Mostly' and 'Somewhat'.

IMPLICATIONS

Several modifications have been made to the survey form for the 2004 MR Services Family Survey in order to reduce sources of error. As noted in the report, about 15% of the forms were returned with a nonusable provider ID; either the field contained an invalid ID, was left blank, or in some instances the wrong form was used. To mitigate this problem, 40 separate teleforms were created with the provider ID pre-filled, and each CSB was mailed copies of their specific form. Fields that are not being used, such as the client ID or Medicaid number were removed from the form to streamline the survey process. Almost 20% of the forms could not be scanned, and had to be hand-entered, increasing the chances of data entry-related error. Monitoring of surveys as they are returned to OMR should allow for feedback to CSBs to correct difficulties caused by improper copying of survey forms. This new form for 2004 will also afford comparison information between waiver and non-waiver services.

Comparing methods of survey administration, it is clear that the method utilized in 2000 where three mailings were utilized, resulted in a higher response rate (62%). The current response rate of 10.6% is even lower than the previous year (17.8%). The current method utilizing face-to-face transfer of the survey at the annual team meeting may not be the best method to insure quality survey results. Furthermore, studies have shown that satisfaction surveys administered by staff show higher rates of satisfaction than surveys that are self-administered or administered by mail. In the future, staff development training should be implemented to help emphasize with staff the importance of families completing the survey and completing it correctly.

The data were analyzed at the state level and can reflect only trends across the state based on the limitations discussed. Several limitations prevent conclusive interpretation of these findings. First, the results of this survey reflect the perceptions of only those family members/guardians who had a family member with mental retardation with active case management, and who chose to complete the survey. Because family members/guardians without consumers receiving active case management services were not surveyed, these results cannot be generalized to all family members/guardians with consumers served by CSBs. Therefore, these results should only be compared with survey results from surveys utilizing similar methodology.

The National Core Indicators (NCI) data comparison (2002-2003) revealed that families in Virginia consistently rated items higher than the other six states who reported on the two surveys for families with individuals who live in the home and live outside the home. Approximately 54% of the respondents for the Virginia survey had family members living at home with them, giving an equal viewpoint from both living situations. There are an additional six states whose data for NCI Family Guardian Survey (living outside the home) are in the process of being compiled. In the future, comparisons to additional NCI data will be helpful for assessing how Virginia stands with national trends.

Despite these limitations, the survey clearly contributes a greater understanding of family member/guardian perception about publicly funded mental retardation services. The surveys will be important contributions to continuous improvement for the CSBs for both Waiver and Non-Waiver services.

APPENDIX



MENTAL RETARDATION SERVICES FAMILY SURVEY

Please answer each question by completely filling in the circle that best represents your situation. Please choose only ONE response for each question.

Shade Circles Like This--> ●

Not Like This--> ○

CASE MANAGER: Please fill in the unique identifier for the consumer below. Fill it in exactly as it appears in your CSB's records. Please do not add "0's" to the beginning or to the end of the identifier that do not appear in your records.

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1. What is your age (the age of the person filling out the survey)?

- ☐ Under 18 ☐ 18-22 ☐ 23-59
☐ 60-64 ☐ 65-74 ☐ 75+

2. About how often do you see the person with mental retardation?

- ☐ Lives with me ☐ Once/month ☐ Once/year
☐ Once/week ☐ A few times a year ☐ Less than once/year

3. What is your relationship to the person with mental retardation?

- ☐ Parent (biological or adoptive) ☐ Husband/Wife
☐ Brother/Sister ☐ Other

4. What is the gender of the person with mental retardation?

- ☐ Male ☐ Female

5. What is the race of the person with mental retardation?

- ☐ Alaskan Native
☐ Asian or Pacific Islander
☐ White, Non-Hispanic
☐ American Indian
☐ Black/African America, Non-Hispanic
☐ Hispanic
☐ Other

Please fill in ONE circle for each question below that best describes your opinion about mental retardation services. Choose only ONE answer.	Yes/ Mostly 1	Some- what 2	No, Not at All 3	Don't Know 4	Does Not Apply 9
1. Do you feel that where the person with mental retardation goes during the day is a healthy and safe environment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Do you feel that where the person with mental retardation lives is a healthy and safe environment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. If the person with mental retardation does not speak English or uses a different way to communicate, (ex. sign language or communication board), do you feel that there are enough staff available who can communicate with him/her?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Do you feel that the person with mental retardation has access to the special equipment or accommodations that he/she needs (ex. wheelchairs, ramps, communication boards)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Do you feel that supports and services are available for the person with mental retardation when needed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Do you feel that services provided to the person with mental retardation have helped him/her to reach planned goals over the past year?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Do you feel that services provided to the person with mental retardation have helped him/her to gain at least one new skill or ability over the past year?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Overall, are you satisfied with the services and supports the person with mental retardation currently receives?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Have frequent changes in staff who work directly with the person with mental retardation been a problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For Official Use Only:

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Go to next side to complete survey

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MENTAL RETARDATION FAMILY SURVEY

Page two

Please fill in ONE circle for each question below that best describes your opinion about the mental retardation services you and/or your family member received. Choose only ONE answer.	Yes/ Mostly 1	Some- what 2	No, Not at All 3	Don't Know 4	Does Not Apply 9
10. If you or the person with mental retardation ever asked for the agency's assistance in an emergency or crisis, was help provided right away?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Do staff help the person with mental retardation get supports in the community, such as services offered through recreation departments or churches?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Overall, has the case manager been helpful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Have frequent changes in case managers been a problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Over the past year, have the services provided to the person with mental retardation helped to relieve stress on your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Did you get enough information to help you participate in planning services for the person with mental retardation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Did you help develop this person's yearly plan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Can you contact the case manager whenever you want to?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. When you ask the case manager for assistance, does he/she help you to get what you need?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Do you help choose the <u>agencies or providers</u> that serve the person with mental retardation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Do you help choose the <u>support staff</u> that work directly with the person with mental retardation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Do staff talk to you about different ways to meet your family's needs?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Do staff respect your family's choices and opinions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Are there enough agencies that provide services to people with mental retardation in your area so that you may choose one in addition to your local community services board?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Are you satisfied with the way complaints about services are handled?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. Overall, do you feel that the person with mental retardation is better off this year than last year, the same as last year, or worse than last year (behavior, attitude, happiness)?

☐ better off this year ☐ the same as last year

☐ worse than last year

26. Do you feel that CSB services have had a positive impact, no impact, or a negative impact on the person with mental retardation this past year?

☐ positive impact ☐ no impact

☐ negative impact

27. Overall, do you feel that the person with mental retardation's progress has been better than expected, same as expected or not as good as expected?

☐ better than expected

☐ same as expected

☐ not as good as expected

**Thank you for taking the time to complete this survey.
Please return in the enclosed, pre-paid envelope.**

For Official Use Only:

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CSB Code 0 1 2 3 4 5 6 7 8 9

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Table 6: Demographic Data

<i>Age Group of Survey Respondent</i>	2002		2003	
	Count	Percent	Count	Percent
Under 18	8	0.6	9	0.9
18-22	20	1.6	21	2.2
23-59	762	59.9	584	61.3
60-64	166	13	128	13.4
65-74	225	17.7	133	14
75+	92	7.2	77	8.1
TOTAL	1273	100	952	100

<i>Frequency of Visitation w. Consumer</i>	2002		2003	
	Count	Percent	Count	Percent
Lives With Me	642	51.4	503	53.4
Once Per Week	290	23.2	236	25.1
Once Per Month	191	15.3	128	13.6
A Few Times Per Year	115	9.2	57	6.1
Once Per Year	6	0.5	10	1.1
Less Than Once Per Year	5	0.4	8	0.8
TOTAL	1249	100	942	100

<i>Relationship to Consumer</i>	2002		2003	
	Count	Percent	Count	Percent
Parent	812	63.9	613	64.4
Sibling	206	16.2	152	16
Spouse	9	0.7	3	0.3
Other	243	19.1	184	19.3
TOTAL	1270	100	952	100

<i>Gender of Consumer</i>	2002		2003	
	Count	Percent	Count	Percent
Male	701	55.4	497	54.9
Female	565	44.6	408	45.1
TOTAL	1266	100	905	100

<i>Race of Consumer</i>	2002		2003	
	Count	Percent	Count	Percent
Alaskan Native	1	0.1	0	0
Asian or Pacific Islander	22	1.8	14	1.6
White, Non-Hispanic	894	72.4	637	73.1
American Indian	9	0.7	2	0.2
Black/African American, Non-Hispanic	285	23.1	202	23.2
Hispanic	10	0.8	7	0.8
Other	14	1.1	10	1.1
TOTAL	1235	100	872	100

Table 7: Percentage of Survey Respondents Expressing Satisfaction

<i>Gender of Consumer</i>	Family Inv.		Case Mgmt.		Choice/ Access		Healthy Environment		Reliability		Other	
	%	N	%	N	%	N	%	N	%	N	%	N
Female												
2003	46.40%	390	86.50%	394	68.50%	394	88.10%	405	52.10%	286	67.60%	407
2002	38.90%	547	84.60%	538	62.50%	550	87.70%	562	5.00%	422	59.90%	564
Male												
2003	44.50%	479	84.20%	476	65.50%	487	87.80%	493	52.60%	350	60.70%	496
2002	37.90%	675	83.20%	679	67.60%	689	87.10%	696	5.00%	541	61.20%	701

<i>Race of Consumer</i>	Family Inv.		Case Mgmt.		Choice/ Access		Healthy Environment		Reliability		Other	
	%	N	%	N	%	N	%	N	%	N	%	N
White Non-Hispanic												
2003	44.90%	613	85.20%	613	66.10%	620	89.50%	630	48.20%	456	62.00%	635
2002	38.90%	874	83.60%	866	64.40%	882	88.70%	891	5.10%	688	59.60%	894
Hispanic												
2003	28.60%	7	71.40%	7	71.40%	7	85.70%	7	50.00%	4	57.10%	7
2002	50.00%	10	90.00%	10	70.00%	10	60.00%	10	0.00%	9	70.00%	10
African-American												
2003	48.50%	194	86.90%	198	67.20%	198	84.60%	201	64.90%	151	74.30%	202
2002	36.30%	273	84.00%	269	68.20%	274	85.50%	282	4.20%	213	66.00%	285

<i>Age Group of Survey Respondent</i>	Family Inv.		Case Mgmt.		Choice/ Access		Healthy Environment		Reliability		Other	
	%	N	%	N	%	N	%	N	%	N	%	N
18-22												
2003	70.00%	20	70.00%	20	52.40%	21	76.20%	21	38.50%	13	61.90%	21
2002	57.90%	19	95.00%	20	47.40%	19	90.00%	20	14.30%	14	60.00%	20
23-59												
2003	46.40%	562	83.50%	565	63.40%	568	87.50%	578	48.90%	425	62.50%	581
2002	40.10%	733	82.10%	737	63.80%	748	85.30%	756	6.20%	594	61.90%	762
60+												
2003	40.00%	325	86.40%	323	69.70%	330	89.30%	336	55.70%	230	64.00%	336
2002	34.60%	471	86.10%	461	69.00%	474	90.50%	483	3.40%	355	59.40%	483

<i>Frequency of Visitation with Consumer</i>	Family Inv.		Case Mgmt.		Choice/ Access		Healthy Environment		Reliability		Other	
	%	N	%	N	%	N	%	N	%	N	%	N
Lives With												
2003	51.10%	487	84.90%	490	60.90%	489	91.40%	501	56.70%	365	63.80%	503
2002	45.10%	628	82.40%	630	59.50%	627	90.60%	638	4.70%	494	62.10%	642
Once Per Week												
2003	44.20%	233	81.40%	231	64.70%	232	84.70%	235	39.90%	168	63.40%	235
2002	36.00%	278	83.90%	280	66.90%	287	81.70%	289	6.40%	220	60.00%	290
Once Per Month												
2003	30.80%	120	87.60%	121	74.00%	127	81.90%	127	45.90%	98	60.20%	128
2002	32.40%	188	85.70%	182	70.50%	190	88.00%	191	6.30%	144	58.10%	191

	Family Inv.		Case Mgmt.		Choice/ Access		Healthy Environment		Reliability		Other	
	%	N	%	N	%	N	%	N	%	N	%	N
A Few Times Per Year												
2003	28.30%	53	85.20%	54	86.00%	57	91.20%	57	62.90%	35	66.70%	57
2002	21.30%	108	86.20%	109	81.30%	112	86.00%	114	4.50%	88	62.60%	115
Once Per Year												
2003	0.00%	8	85.70%	7	77.80%	9	90.00%	10	50.00%	4	55.60%	9
2002	0.00%	6	100.0%	6	100.0%	4	83.30%	6	16.70%	6	100.0%	6
Less Than Once Per Year												
2003	0.00%	6	80.00%	5	66.70%	6	60.00%	5	0.00%	3	42.90%	7
2002	0.00%	5	100.0%	3	100.0%	5	100.0%	5	0.00%	2	60.00%	5

	Family Inv.		Case Mgmt.		Choice/ Access		Healthy Environment		Reliability		Other	
<i>Relationship to Consumer</i>	%	N	%	N	%	N	%	N	%	N	%	N
Parent												
2003	46.20%	597	85.00%	595	62.30%	599	89.40%	611	48.30%	435	61.50%	611
2002	37.80%	796	82.80%	793	62.20%	797	87.60%	808	4.50%	628	59.00%	812
Sibling												
2003	31.50%	146	81.10%	143	68.50%	146	87.20%	149	52.80%	106	62.70%	150
2002	33.30%	204	82.10%	195	67.20%	204	84.00%	206	7.10%	154	60.20%	206
Spouse												
2003	66.70%	3	100.0%	3	66.70%	3	66.70%	3	33.30%	3	66.70%	3
2002	25.00%	8	62.50%	8	87.50%	8	100.0%	8	0.00%	7	55.60%	9
Other												
2003	50.60%	170	85.10%	174	72.90%	181	84.50%	181	61.50%	130	68.50%	184
2002	45.90%	218	88.10%	226	73.60%	235	89.20%	241	7.30%	177	68.30%	243

	Family Inv.		Case Mgmt.		Choice/ Access		Healthy Environment		Reliability		Other	
<i>All</i>	%	N	%	N	%	N	%	N	%	N	%	N
2003	44.80%	937	84.70%	936	65.40%	951	88.20%	967	51.40%	691	63.20%	972
2002	38.40%	1267	83.80%	1263	65.30%	1284	87.50%	1302	5.40%	994	60.80%	1313